

The New Face of Alzheimer's

I am the new face of Alzheimer's, my Grandparents had Alzheimer's, my father had dementia, my Mother has Alzheimer's, and I may eventually have Alzheimer's. I am a nurse and I have many patients with this disease. The lack of financial support leads to families moving to take care of family members with this disease. Moving is not easy, but it is harder for the patient to be moved around to new environments. The family that moves to take care of a loved one goes through a lot of emotional and financial stress, leaving a job, a home and losing benefits from a former job is just the beginning. Once you have moved and get settled you find you may be up all night with a patient who has sundowners, you need locks to keep them inside, disconnect or disable appliances, cooking, cleaning, bathing, dressing, it is a 24 hour 7 day a week job. Many patients need to have constant care to keep them safe and to prevent them from destroying or throwing away keepsakes and valuables. What your loved one has worked all his or her life for must be spent to get any financial assistance, and even then it is difficult to find a facility that will take Medicaid. Most facilities have a small locked unit void of any activities and very little help. Real life is not like the movies, these patients deal with a lot of aggressive behaviors. When they start losing communication skills, they refuse meds, baths, they will not eat, and they wander. They need stability the fewer the moves the better, with each move comes adjustments and if you cannot keep them home you may move to several different places to find the right one. Caregivers need as much or more help financially and emotionally. Caregivers wear out. They have no life outside of taking care of the family member, everything is very costly and rarely can you get help in a rural area. Having someone come in for a couple of hours is hardly enough time to take a nap let alone get your hair done, go to lunch, or to your own doctor's appointments. Home health is great but time is limited, hospice is great but only available for Alzheimer patients at the very end of the disease, respite care is costly and can be very disruptive to the patient who has to leave home for this, as well as day care if you can find one that you can afford and your loved one enjoys. Caregivers give up their own lives, vacations, rest, jobs, income, insurance; we do not help these families enough. We need to pay these family members to be caregivers. They do a better job than a stranger and not all facilities take Alzheimer's or dementia patients. Rural areas are underserved, Montanans are cheated out of the benefits that larger populations have because of lack of resources. We need change if we are to take care of a growing population of Alzheimer patients. Locked rooms with little or no interaction or help is not the answer. We need larger facilities that can accommodate the changing needs of the patients and their family, units that can be transitioned too as their needs change. We need help with insurance companies that give empty promises and tons of paper work to fill out. We need to get assistance that was promised and help finding a Doctor that will fill out the papers month after month. We need help with the cost of medications that put us in the donut hole so we stop taking it, making the problem worse. We need to help our aging parents live out the rest of their lives with dignity and free of pain, and we need to help the caregivers so they can continue to be supportive to their loved ones.

1. Paying family members to be caregivers
2. Help filling out insurance forms
3. More facilities in rural areas with transitional care
4. Support groups for caregivers
5. Day care and respite care

Thank you for your time,

Sharyl L. Zahn, the new face of Alzheimer's